GLENWOOD AND WOODWARD RESOURCE CENTERS
ANNUAL REPORT OF BARRIERS TO INTEGRATION

Calendar Year 2019

Introduction

Purpose of this report:

The Department of Justice settlement with the state Resource Centers (RCs) in November 2004 includes an agreement that the major barriers to each individual's move to the most integrated setting will be identified. The information is to be collected, aggregated, and analyzed. Annually the information is to be used to produce a comprehensive assessment of barriers that is provided to the Mental Health and Disability Services Commission and other appropriate agencies. Per the settlement, "If this information indicates action that the State can take to overcome barriers, taking into account the statutory authority of the State, the resources available to the State and the needs of others with mental disabilities, a plan will be developed by the State and appropriate steps taken."

Subject of this report:

This report contains data about the identified barriers of all persons residing in the Resource Centers' Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IDs) programs as of December 31, 2019 and who have been identified as having at least one barrier to moving from the campus to a community setting. The data, analysis, and actions are for Glenwood Resource Center (GRC) and Woodward Resource Center (WRC) combined.

Number of Individuals Residing at Resource Center ICF/IDs
(December 31, 2019)

	Adults	**Under Age 18**
GRC	195	1
WRC	126	4
Total	321	5

Definition of barrier:

Barriers are defined as "what prevents an individual from living in the community." These barriers indicate there is a need to continue to increase community service providers' capacity to effectively meet the needs described in the barriers and help to address concerns of the individual, guardian or legal representative regarding living successfully in an integrated community setting.

Barrier Data and Discussion

Major Barrier Prevalence

(A person may, and often does, experience more than one barrier category)

Barrier	Definition	Minor %	Adult %
Problematic behavior makes it difficult to ensure safety for self and/or others	The person has significant problematic behavior that requires supports for a person's safety or the safety of others. Problematic behaviors most commonly included in this category are physical aggression, leaving the home or work area without notifying staff if unsupervised time creates a risk of harm to self or others, problematic sexual behavior, destruction that may be dangerous to self or others, and various forms of self-injury. An infrequent but extremely dangerous issue is fire setting.	WRC 4/4 100% GRC 1/1 100% Total 100%	WRC 90/126 71% GRC 132/199 66% Total 68%
Under-developed social skills	The ability to practice what community members commonly consider appropriate social skills is significantly impaired and affects the person's housing, jobs, support staff, or housemates. Examples include extreme disruptive behavior, repeated verbal threats that result in concerns about safety for others, multiple unfounded accusations against staff, repeatedly invading personal space, loud or rude behavior that results in others not wanting to live with the person, inappropriate touch, inability to interact with others, inappropriate urination, and disrobing in public.	WRC 3/4 75% GRC 1/1 100% Total 80%	WRC 24/126 19% GRC 43/199 22% Total 21%
Health and safety	The person has multiple, severe, and/or sensitive health concerns that contribute to very fragile health and complex health care needs. The person may be unable to verbally report symptoms or accurately identify and request assistance with symptoms that could indicate that their health is at risk. The person may require specialized medical treatment and/or monitoring that is not readily available in the area of choice or the level of care they would prefer (e.g. assistance with monitoring and administering injections for diabetes, fast and frequent access to monitoring/adjustment of adaptive equipment, nutrition and medication via g-tube, prn medication for seizures).	WRC 0/4 0% GRC 0/1 0% Total 0%	WRC 13/126 10% GRC 57/199 29% Total 22%

Barrier	Definition	Minor %	Adult %
Individual, family or guardian reluctance	Individual, family and guardian reluctance to moving from RC environment to community supports. Examples of concerns cited are community providers' ability to provide the level of support necessary for success, lack of a safety net when support needs become more intense, family member has lived in the RC setting for many years and considers it to be their home, difficult adjustment to change, community ability to provide the medical support and consistency of care as provided at the RC, not successful in community in the past, lack of well trained, consistent, familiar staff, safety of the community.	WRC 0/4 0% GRC 0/1 0% Total 0%	WRC 71/126 56% GRC 164/194 82% Total 73%

Discussion

Category: Safety due to Problematic Behavior

This includes safety of the individual, as in areas of self-injury, leaving the home or work area without notifying staff if unsupervised time creates a risk of harm, behavior toward others that invites others to cause harm to the individual, or lack of understanding of situations that place the individual at risk. A second, but equally important concern is safety of others, such as situations involving aggression, sexual assault, or fire-setting. Examples of self-injury include cutting self, swallowing items, inserting items in a bodily cavity, suicide threats and/or attempts, polydipsia, ingesting things not meant to be edible or unsafe food such as from the garbage or including the wrapper, purposeful falls. The cost and ability to hire and maintain staff and training to provide these supports at the frequency, consistency, or level of need for the individuals served in the RCs often can be a challenge, especially for community providers. To be included in this category, interfering behavior(s) have been determined to currently be at a level of frequency or intensity that the supports needed are greater than are commonly offered by community providers. The percentage of people experiencing this barrier rose for a number of years at 60% in 2014, 61% in 2015 and 2016, 64% in 2017, and 68% in 2018 and 2019. The GRC waiver data was accidently included in the 2018 number. The rise for many years is a reflection of the practice that people moving into the Resource Centers are those for whom a state wide search results in no community provider available. The implementation of tiered rates for HCBS ID Waiver with a significantly higher rate for the top tier may be beginning to impact this positively.

Category: Underdeveloped Social Skills

This area has to do with a need for further social skill development. Disruptive behavior is at a level of intensity that people around the person are unwilling or unable to tolerate living, working or socializing with the individual and making it very difficult for the individual to find housing, work, and staff support. Housemates may not have the opportunity to participate in activities because this person has to be removed from social events. The provider may have difficulty maintaining consistent staff due to burn out or repeated threats and accusations. Staff may have difficulty supporting others in the setting because of the intensity of need of this person. The number of people experiencing this barrier decreased from 35% of adults in 2012

to 25% in 2013, 11 % in 2014, and 8% in 2015. The number increased slightly to 9.6% in 2016 and significantly to 20% in 2017, staying steady at 20% in 2018, and 21% in 2019. The significant increase in 2017 may be due to a closer look at some of the people who have reluctant guardians and whether there were additional barriers beyond guardian reluctance. GRC waiver data was accidently included in the 2018 number.

Category: Health

This category has to do with individuals with significant medical needs. Often these individuals are older and are medically fragile; they frequently experience communication difficulties and rely on staff who knows them well enough to understand non-verbal signals and recognize signs of discomfort or medical need. Health is fragile enough that without staff ability to quickly recognize early and subtle signs of illness, the persons' health would be quickly compromised. Some individuals use a g-tube for nutrition, hydration, and medication. Some individuals require prn medication for seizure activity. Many individuals use extensive adaptive equipment. Homes need to have space and accessibility. For some individuals, quick access to adjustment and repairs for adaptive equipment (lifts, wheelchairs, bath carts, etc.) is essential for maintaining health. Individuals also rely on supports provided by quick access to professionals available at the RCs (doctors, nurses, physical, occupational and speech therapists on grounds or on call). It is difficult for many guardians to consider a move to a setting where those resources may not be as readily available. The number of people experiencing this barrier was 30% of adults in 2011, 2012, and 2013 and decreased to 22% in 2014, 20% in 2015, and 16% in 2016. There was a slight increase to 17% in 2017, 21% in 2018, and 22% in 2019. The earlier decreasing trend may have in part been due to more accurately determining what things are actually barriers, some individuals passing away and some individuals moving to hospice or a skilled health care setting. The increase for a couple of years may be a reflection of those who have lived at the Resource Centers for many years continuing to age.

Category: Family/Guardian Reluctance

The two most frequent concerns expressed by guardians of individuals living at the Resource Centers are that community services will not provide as good a quality of service, be unable to safely support significant problematic behavioral issues as evidenced by past experience of multiple discharges, and lack well trained consistent staff. The other is that individuals will not have the needed nursing and medical care such as they receive at the Resource Center. Other reasons expressed for reluctance include: lack of a safety net return to the RC if unsuccessful; familiar and trusted staff; the individual is happy, this is home, don't disrupt that and cause significant stress and loss; safety of the community if the person doesn't have the level of supervision needed; law enforcement involvement and possibly prison time if the person doesn't have the level of supervision needed; honoring the wishes of a deceased parent; lack of trust in the managed care system; and psychiatric care. A few individuals also express that they do not want to move. Family members often react emotionally when approached about transitions to community services; they talk about their fears that a move to a community setting may not last, that their loved one will experience a long-term hospitalization due to a lack of enough community services to meet their support needs or that family members will be required to provide a home and care without enough support available to them. Family members express concern that the health of their loved one will be in jeopardy without the health care services at the RC and the trained, long term staff who know the

person well and can identify early signs of a health concern. The number of people experiencing this barrier increased from 61% of adults in 2012 to 68% in 2013. The percentage continued nearly steady at 69% in 2014 and 68% in 2015 and 2016. In 2017 there was a decrease to 60% and in 2018 to 54%. Probable reasons for this decrease are many years of continued efforts by the social workers talking with guardians about discharge planning, some individuals who had lived at the RCs many years passing away, and the guardians of quite a few of the people who moved into a RC in the past few years support the person moving out again when a provider is able to meet their needs. This willingness does sometimes fade as the person does well. Guardians comment that the person is doing the best they ever have and are happy and they don't believe that will continue if the person moves out. In 2019 there was an increase to 73%. In looking at the data again this year, we realize the data for GRC in 2018 was incorrect.

Additional Comments:
Lack of jobs or day activity continues to be a concern. A meaningful day is important for everyone and a key to success for many people, whether employment related or in a structured activity or volunteer setting. Meaningful day activity may be important for self-esteem, social, earning, and structure of the day. Lack of meaningful activity often leads to difficulty with problematic behaviors.

Another barrier we continued to hear identified by community providers is difficulty finding staff to hire in order to support current programs or to expand services.

We initially observed changes in the service system which appeared to be in response to managed care and the implementation of tiered rates for ID waiver. Providers consolidated and more waiver service settings increased to serving four people instead of three. Toward the end of 2019, we started to see some provider expansion in the HCBS ID waiver programs with existing providers. Additionally, the higher tiers appear to be attracting some providers who are looking to exclusively serve people who are a Tier 5 or 6. We don't have experience yet to tell us if this will be effective. Host homes are also becoming more prevalent.

Regional Preference by Age Range & Gender

Some individuals have specified geographically where they would prefer to live. The following table provides that information by age and gender within regions of the state. See Appendix A for a map.

REGION	AGE RANGE	MALE	FEMALE	Total
Central Iowa	Under 18	1	0	1
	18 to 25	2	0	2
64	26 to 40	17	8	25
	41 to 65	21	5	26
	Over 65	5	5	10
East Central Iowa	Under 18	0	0	0
	18 to 25	3	1	4
17	26 to 40	5	1	6

REGION	AGE RANGE	MALE	FEMALE	Total
	41 to 65	3	0	3
	Over 65	1	3	4
North Central Iowa	Under 18	0	0	0
	18 to 25	0	0	0
	26 to 40	1	1	2
10	41 to 65	3	2	5
	Over 65	2	1	3
Northwest Iowa	Under 18	0	0	0
	18 to 25	1	0	1
5	26 to 40	2	0	2
	41 to 65	1	0	1
	Over 65	1	0	1
Northeast Iowa	Under 18	0	0	0
	18 to 25	1	1	2
14	26 to 40	6	0	6
	41 to 65	3	1	4
	Over 65	1	1	2
South Central Iowa	Under 18	0	0	0
	18 to 25	0	0	0
	26 to 40	0	1	1
2	41 to 65	1	0	1
	Over 65	0	0	0
Southeast Iowa	Under 18	1	0	1
	18 to 25	1	0	1
6	26 to 40	2	1	3
	41 to 65	1	0	1
	Over 65	0	0	0
Southwest Iowa	Under 18	1	0	1
	18 to 25	1	0	1
31	26 to 40	2	9	11
	41 to 65	17	1	18
	Over 65	0	0	0
West Central Iowa	Under 18	0	0	0
	18 to 25	1	0	1
4	26 to 40	2	0	2
	41 to 65	0	0	0
	Over 65	1	0	1
Out of State	Under 18	0	0	0
	18 to 25	0	0	0
2	26 to 40	1	0	1
	41 to 65	1	0	1
	Over 65	0	0	0
Whole State	Under 18	1	0	1
	18 to 25	1	0	1

REGION	AGE RANGE	MALE	FEMALE	Total
5	26 to 40	2	0	2
	41 to 65	1	0	1
	Over 65	0	0	0
No Preference Identified 181	Under 18	1		
	18 to 25	3		
	26 to 40	31		
	41 to 65	103		
	Over 65	43		

Actions this Reporting Period

Overall

- IA Health Link, has been effective since April 1, 2016. UnitedHealthcare (UHC) ended June 30, 2019 and Iowa Total Care started July 1, 2019. Amerigroup continues since the implementation of Iowa Health Link. Many individuals who previously had UHC were able to keep the same case manager. For individuals with a new case manager, the Resource Centers provided information to help the new case manager get to know the individual. Social workers provided information to the case managers for all individuals where records did not transfer between Managed Care Organizations (MCOs) as UHC ended. The case managers from the MCOs cover most individuals living at the Resource Centers (RCs). The MCO Case managers assigned to individuals at the Resource Centers are invited to participate as Interdisciplinary Team (IDT) members. Involvement by the case managers has varied. In 2019, Iowa Total Care has tended to be more actively involved on campus than Amerigroup. Both are available to do parts of the transition process once a provider is identified. Iowa Total Care has been more active in assisting to find a provider for some individuals.
- Continued to welcome providers to meet with us to learn about the support needs of individuals living at the RCs and to encourage new providers or expanding providers to develop services in areas identified by families as needed
- Providers continued to visit people on campus and individuals continued to visit providers.
- The Money Follows the Person Grant (MFP) was scheduled to end December 31, 2019 and were not able to take any new referrals in 2019. The program has now been extended another year. We continued to communicate with MFP for people with an assigned transition specialist and worked with MFP in the statewide stakeholders group. MFP transition specialists provided us some information about provider openings.

- Prepared for changes in transition planning which would occur when MFP was scheduled to end.

Problematic Behavior and Underdeveloped Social Skills

- Provided therapy and counseling support services at the RCs within groups and individually. Some topics and interventions include social skills; Dialectical Behavior Therapy (DBT) skills including mindfulness, anger management, and interpersonal communication skills; human sexuality; sex offender; social boundaries; reality therapy, victim support; positive life skills; relationships; problem solving.
- Used the trauma screening tool to ensure that all mental health needs are being covered for the persons in residence at GRC.
- Provided training in some DBT skills for new staff at orientation and offered this training as needed to individual team members.
- WRC provided staff training on "The Struggle Switch" from Acceptance and Commitment Therapy (ACT) at the 2019 staff Skills Fair.
- Susan Smith trained some GRC direct support and professional staff on ACT concepts.
- WRC's Behavioral Empirically Supported Therapy Team (BEST) continued the expansion of behavioral services to include numerous supports and strategies which are rooted in ACT and were custom designed to match the goals, values, and skills of individuals receiving services at Woodward Resource Center.
- WRC implemented an 8 hour staff training on ACT.
- Expanded WRC and GRC psychologist skills through joint literature review related to Relational Frame Theory/Mastering the Clinical Conversation.
- Two psychologists at WRC are Board Certified Behavior Analysts.
- WRC provided services to individuals on campus in the area of problematic sexual behavior through the APPLE team which included staff trained by the Iowa Board for the Treatment of Sex Abusers (IBTSA). Four members are certified by IBTSA. Additional members are in the training process.
- WRC staff made two presentations at the 2019 IBTSA In-service.
- An APPLE team member serves on the IBTSA Board.
- An APPLE team member is a member of the Association for the Treatment of Sexual Abusers (ATSA).
- The APPLE team was available for consultation and training to community providers.
- Continued using Footprints, Good Lives, and incorporating ACT concepts in working with individuals with problematic sexual behavior.
- Three staff are certified to administer and interpret the Abel-Blasingame Assessment System **(**ABEL) for sexual preference to assist in treatment and supporting individuals with sexual offending behavior.

- Two APPLE team staff attended a Department of Corrections sponsored "Achieving Change Through Value-Based Behavior (ACTV) Pre-service training", a model of ACT for individuals who have offended.
- Collectively, WRC Psychologists
    - 1) attended the 2019 Iowa ABA Conference and the 2018 Iowa Mental Health Counselors' Association Conference,
    - 2) have membership with Iowa Association for Behavior Analysis and the Association for Contextual Behavioral Science,
    - 3) obtained training to provide supervision to Board Certified Behavior Analysts,
    - 4) attended trainings/webinars on "Gender Dysphoria; DNA-V (ACT model for youth); ACT for individuals with Intellectual Disabilities; Teaching Learners with Autism to Cooperate with Medical Procedures; Maximizing Independence during Self Cares; Sexual Offending by Females; Sexual Behavior, Functional Assessment and Human Rights; Sexual Health for BCBAs; OBM Systems to Increase Employee Engagement and Decrease Clinician Turnover; Recent Advances in Assessment, Intervention, and Prevention of Behavior Disorders; Assessing and Treating Pediatric Sleep Disturbances; Female Sex Offenders; Group Therapy with Those Who Sexually Abuse; Working with Women who are Sexual Abusers; Relational Frame Theory and Behavioral Flexibility Training; Treatment of Automatically Reinforced SIB; Evidence Based Trauma Treatments and Interventions; 10 Core Competencies of Trauma, PTSD, Grief and Loss; Trauma Informed Care for Behavior Analysts; Help Your Staff Be the Best They Can Be: Behavioral Skills Training; Blank Children's STAR Center Spring Workshop Series.
- Offered consultation and training throughout Iowa, via the "Iowa's Technical Assistance and Behavior Support" (I-TABS) program, to providers, families, and case management who support people who do not live at the RCs. This expands community stakeholder skills, which may increase their ability to maintain people currently living in the community and eventually support individuals moving from the Resource Centers.
    - Consultations: responded to information requests from numerous callers and also provided 55 complete on-site and/or phone consultations.
    - Training: topics include: Autism Spectrum Disorder and Sexually Offensive Behavior, Behavior Analysis, Behavior Analysis Licensure, Functional Assessments and PASRR Behaviorally Based Treatment Plans, Autism Spectrum Disorder-An Introduction; and an overview of available I-TABS services.
    - Accumulatively, the trainings contacted 632 stakeholders from: Iowa Board for the Treatment of Sexual Behavior, PASRR skilled nursing facilities, UnitedHealthcare, Money Follows the Person Partner's, Iowa Total Care, a University of Iowa Pharmacy student, and WESCO Industries.
- I-TABS noted these trends:
    - The number of consultations completed via phone has increased

  - Webinars are most often requested rather than face-to-face to accommodate staffing
  - The case managers who are requesting consultations are often the ones that have previous experience with I-TABS services.
- Agencies received training as part of individuals' transitioning to their services. Topics included such things as individual routines, communication techniques, behavioral support plans, anticipated adjustment behavior. Training involved agency staff spending time at the RCs shadowing RC staff, RC staff spending time at the agency prior to move, day of move, and following move. If the individual had a day activity or job site, RC staff also accompanied individuals there and assisted staff as they helped the person adjust to new tasks and environments. A variety of staff were involved in providing the training such as direct support staff, supervisors, treatment program managers, psychologists, psychology assistants, speech, vocational staff, and social workers. Follow-up training was provided as needed during the transition period.
- The Autism Resource Team continued providing training to all new WRC staff at orientation and consulting to the teams on campus.
- Expanded person centered supports through a structured personal outcomes review based on the Council on Quality and Leadership model at GRC.

Family/Person Reluctance

- Continued sending the guardians/families information about providers from the person's area of choice with the invitation to the person's annual meeting.
- Involved RC staff beyond social workers in visits with providers and follow-up visits to increase staff's comfort level with moves which in turn may increase confidence of families and individuals living at the RCs that community services can be successful in supporting an individual.
- Encouraged and assisted people to identify a preferred area of the state to live in so we can provide more detailed information about services available in that area and encourage guardians to develop relationships with providers and coordinators of disability services in the regions and educate them on the support needs of the individuals.
- Invited families to visit providers with us.
- Shared stories about people who have successfully moved via individual discussions with guardians and family.
- Interdisciplinary teams continued to talk with guardians reluctant to move to obtain more specific information about their concerns in order to address those.
- Social workers continued to familiarize themselves with services and supports available across the state through visits to providers and providers meeting with the social work department on campus. Information about services available are shared with

families/guardians as providers are identified who may be able to meet the needs of each individual.

- Social workers continue to have more frank discussions with guardians on census reduction, house consolidation, and general characteristics of the individuals who typically move into the RCs.
- Discussion with MCO case managers about guardian reluctance and the reasons; some involvement from the case managers in talking with guardians.
- Shared monthly reports with guardians, allowing them to see ongoing progress and the fluid shift in supports needed for the individual.
- Continued discussion of some provider openings at Social Work Department meetings to provide peer feedback and support regarding referrals and discussions with reluctant guardians.

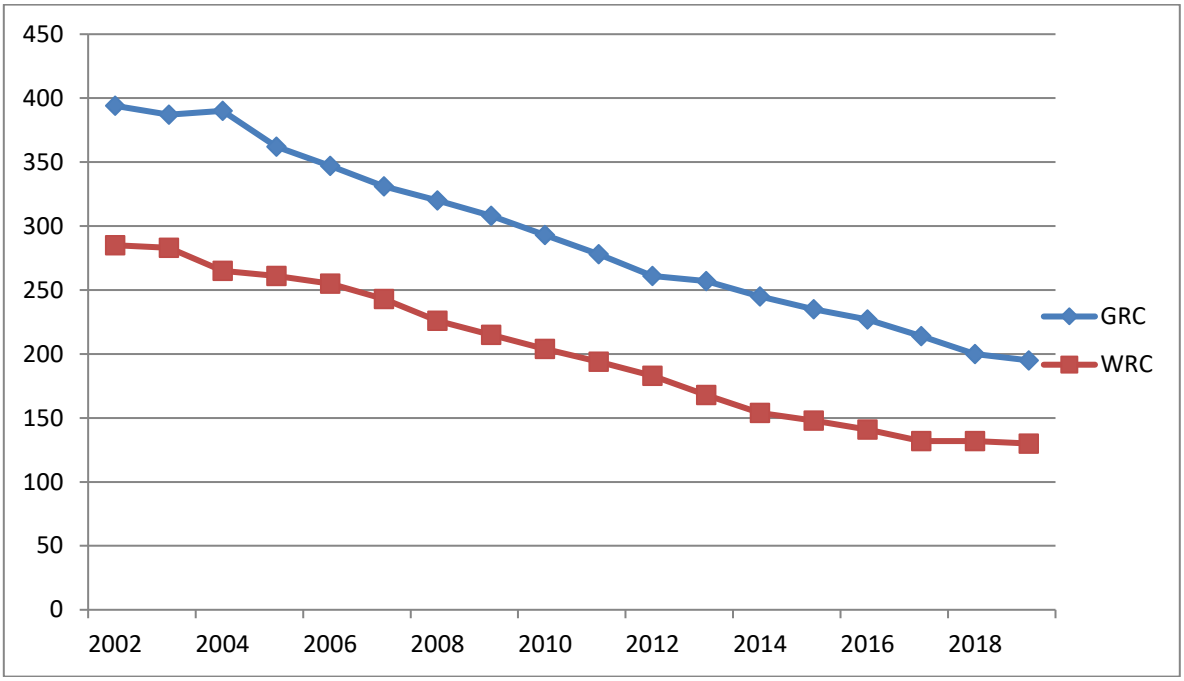
Health

- Continued to share this need with providers as they visit to discuss their services.

Vocational

- Continued to work with the vocational specialist with the MFP grant.
- For some individuals moving out, assured referral to and completion of application for Iowa Vocational Rehabilitation Services (IVRS) prior to move so referral to IVRS in area moving into could be done more quickly once that area was determined.
- Continued to implement changes to the Workforce Innovation and Opportunity Act. This included educating individuals and guardians about the right to work in the community and making referrals to Iowa Vocational Rehabilitation Services as requested.

Census Reduction



The census of the RCs has decreased as people have successfully moved to services with community providers. For a number of years, the RCs have had a specific census goal and have accomplished this through helping people secure services with community providers and helping prevent the need for people to move in.

The RCs are committed to continuing to help people move to and stay in the communities of their choice. Some of the actions taken to accomplish this include:

- Educating others about the RCs' shift in role to shorter rather than long term residential services.
- An RC admission inquiry process that focuses on preventing the need for admission
- Treatment focus on the specific reasons the community providers are unable to support the person.
- Changing practices at the RCs to replicate what people experience living in the community.

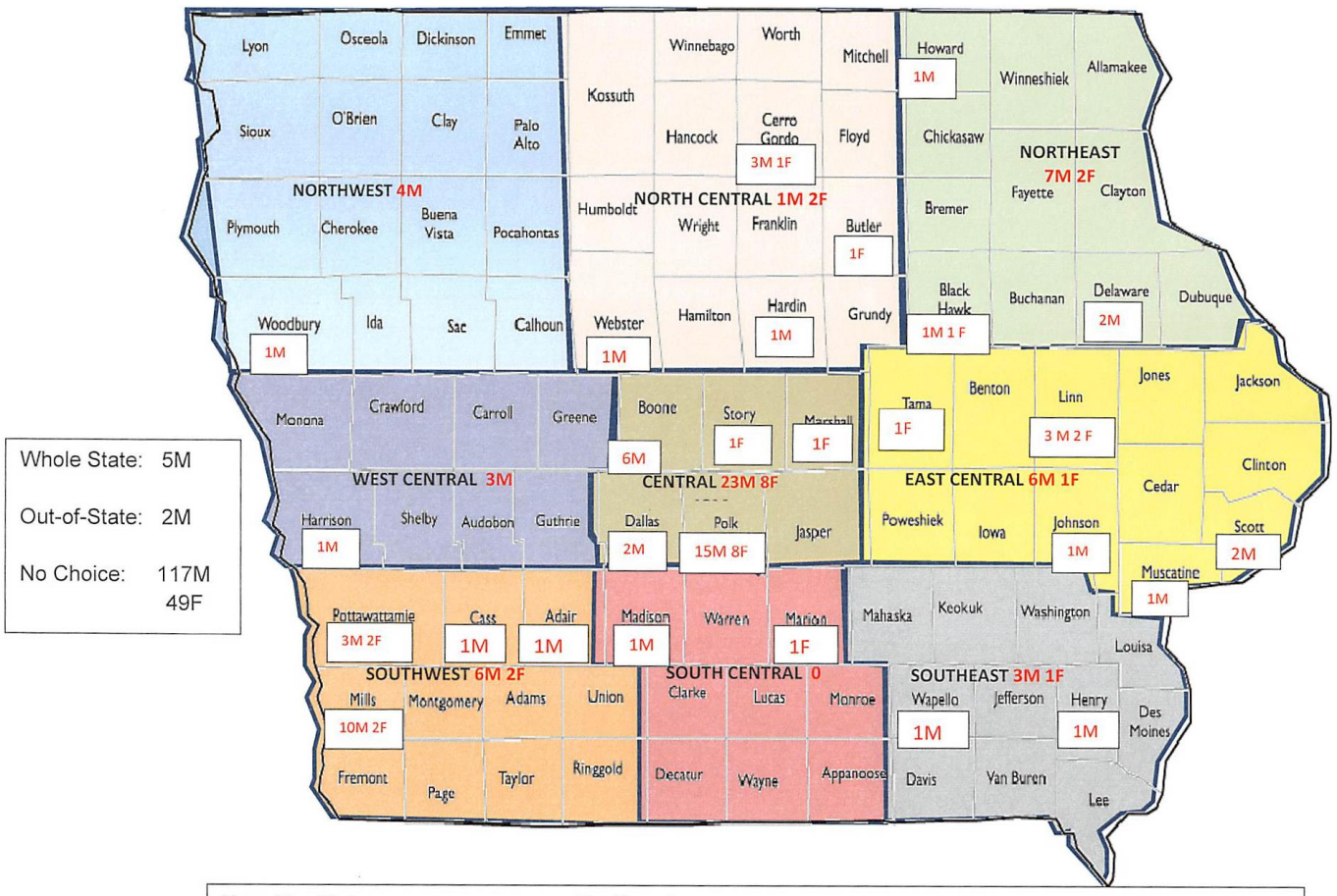
The RCs place an emphasis on ensuring that people are moving with the appropriate services and supports to meet their needs and the moves can therefore be successful. The transition process includes:

- Comprehensive functional assessment to ensure essential supports for health and safety are identified
- A written transition plan developed by the IDT including the person, family/guardian, community provider(s), and case manager and includes a crisis plan.

- An individualized physical transition process that includes the person having visits from the provider staff and making visits to their new home before the move.
- Training of provider staff by the RC staff.
- Follow-up by the RC staff after the move.
- Inclusion of the case manager throughout the planning and move process and transfer of oversight to the case manager for follow-up after discharge from the RC

APPENDIX A

Combined Resource Centers Area of Choice by County Map 12-31-19 Data



Whole State: 5M

Out-of-State: 2M

No Choice: 117M
49F

Key: M = Male F = Female

Numbers by the area rather than a county indicates choice of the general area rather than a specific county